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## The Value of Family Support at the End of Life

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Hannah Butler

Honors Nursing Service-Learning Case Study

Mentor: BJ Garrett

### The Value of Family Support at the End of Life

Many patients seek hospice or palliative care at the end of their lives. Some degree of family support is needed to receive hospice care. Family support can be defined as assistance from a patient's biological family, or from their family of choice. When a patient is dying, those with support often move in with their family to be cared for and to fully live out their last days. A patient can qualify for hospice when they have been given six months or less to live by two physicians. Although palliative care has taken place in inpatient facilities in the past, it is becoming more and more common in the patient's home. At the same time, people are becoming more socially isolated (Ozaki). A lack of family support can make it difficult for patients to receive hospice or palliative care.

One part of end-of-life care is the decision to enroll in hospice. A patient often loses their ability to make decisions at the end of their lives (Sudore). Family members then make decisions for the patient such as the decision to enroll in hospice or the decision to turn off a pacemaker. Even before a patient is unable to make decisions, family members are often involved in supporting the patient in decision making (Sudore). Patients without family support make these decisions alone, or a committee will make a decision on the patient's behalf. The patient not be able to live out the rest of their life at home.

When it is time for an end-of-life decision to be made, it is important for the healthcare providers to consider the emotional and social aspects of the decision. When the physician

pushes decisions on the patient and their family without understanding if they have processed the diagnosis, it can increase anxiety and depression among the patient and their family. Healthcare decisions should be made over a series of conversations that include the healthcare provider, the patient, and the family (Kirchhoff). Family members can support the patient in making decisions which can decrease anxiety.

About 25 percent of patients lack a surrogate decision maker. A surrogate decision maker makes decisions on the patient's behalf when the patient is no longer able to make decisions. This could be because the patient has no close friends and family who are still alive or because no friends or family could be contacted. Some patients lack both an advanced directive and a surrogate decision maker. In this case, an ethics board at the hospital or hospice unit would make decisions for the patient. Patients without family support are at a risk for decreased quality of care, lacking a palliative care consult, chaplain visit, and a do not resuscitate order (Sudore).

In a study of dying veterans, veterans with family support are more likely to have a palliative care consult, a chaplain visit, and a Do Not Resuscitate order. Veterans with family support were less likely to die in an inpatient facility such as an acute care unit or nursing home (Sudore). Those with family support are more likely to die in a hospice unit or at home. This shows that family members help patients access available services. The Do Not Resuscitate order can serve as a means of communication between the family, patient, and physician. Overall, patients with family support have better outcomes.

In the study, veteran patients without family support were found to be younger than those with support. Veterans were found to be much more likely to have family support than the general population. Over 90 percent of veterans have family support while only about 75 percent of the general population has family support (Sudore).

A study of a neurological intensive care unit found that merely documenting a surrogate decision maker upon admission decreased the patient's healthcare costs and length of stay. Patients with a documented surrogate decision maker also were likely to receive less aggressive treatment (Sudore). This is good because without familial support, patients are more likely to undergo unnecessary and intense procedures. These procedures may slightly prolong the patient's life, but at a great cost to the patient's quality of life.

A case study demonstrates the value of family members caring for a patient at the end of their life. A 59-year-old Japanese female had end stage breast cancer and was living alone in a shelter after the Fukushima earthquake in 2011. She wished to receive palliative home care as her condition continued to decline. Unfortunately, she was living in a temporary housing shelter, so this proved to be a challenge. The researchers contacted the patient's sister who moved back to Fukushima to be with the patient. The patient's sister cared for her, and the patient was able to die peacefully at home (Ozaki).

From this, we can learn the importance of taking initiative in helping patients find support. The researchers contacted the patient's sister, and the patient was able to die at home. This goes beyond disaster situations and patients who live alone. As we become more and more isolated, health care providers have the responsibility of reaching out to family members who may be willing to support the patient. As in the case study, finding family support can determine whether the patient is able to die according to their wishes (Ozaki).

It may become harder for patients to receive hospice care with growing trends of social isolation, aging, and depopulation. For a patient to receive hospice care according to their preferences and values, it is practically mandatory they have some kind of family support. Health care providers must take an initiative to help patients find support at the end of life (Ozaki).

Although it is not ideal, many healthcare providers are hesitant to discuss end of life care with their patients (Kurahashi). This is often due to a lack of training. Family members can initiate conversations with their healthcare providers about the patient's goals for the end of their life.

Through my service-learning project with Circle of Life Hospice, I volunteered with a 102-year-old female whose family did not care for her. I also worked at the help desk in the Circle of Life facility and took down Christmas decorations at the end of the season. Because some degree of support is needed for hospice care, I saw no patients with absolutely no support. I also took a class about end-of-life and palliative care and took multiple tours of the Circle of Life facility. On the tour, I was able to listen to a lecture from the palliative care physician at Circle of Life about an overview of hospice care at the Circle of Life facility. In my Palliative and End-of-Life Care class, I learned about the dying process and common fears when a patient is dying.

My patient's husband had died, and she had no children. She did have a stepson, but had very little contact with him or his family. The patient chose to marry later in life because she cared for her parents until they died instead of sending them to live in a nursing home. The patient lived alone in an apartment complex for older adults. She did receive assistance from her pastor and his wife. She would fall into a category of patients with some level of support, but not the level that family or a close friend would provide.

My patient had a stroke and was enrolled in hospice after being given six months or less to live. When I visited her, she seemed very able physically. At one point, she dropped her tissue and bent over and picked it up. She was able to walk well with a walker. My patient had trouble with her short-term memory. Often, we would talk about the same topic three times before I left, and each time she did not know that we had already talked about it. Her memory and cognition

seemed to decline as I visited her, though not rapidly. She had trouble hearing, and it was hard to determine if the patient's conversation was inappropriate because of hearing loss or cognitive decline.

The patient did have a Do Not Resuscitate order, which her pastor likely helped her obtain. She was not visited by a chaplain, but she did see her pastor daily. Hopefully she will be able to die at home. However, it is likely that she will die alone because she lives alone. If she falls or rapidly declines, it is likely that it will be a while before someone finds her. This puts her at risk for poorer outcomes physically and more anxiety at the time of death.

The pastor brings the patient breakfast every morning. Around noon, the pastor's wife will give the patient her medications in a spoonful of applesauce. She clearly cares about the patient but is unable to take care of her around the clock. In the evening the pastor may bring the patient a milkshake or soup for dinner. The patient spends the holidays with her pastor and his family.

My patient does not mind living alone. She says that God is with her and he protects her, and it does appear to be true. On her walls she has pictures of Jesus and pictures of her pastor's family, but no pictures of her own family. If I were her, I would be scared to live alone and upset that my family had left me. The patient, however, says she understands that her son and grandchildren are busy and don't have time to see her.

There are parts of the patient living alone that are concerning. She is unable to lock her door. Because she lives in an apartment complex, people frequently walk by her apartment. Someone could easily walk in and harm her. Once as I was leaving a neighbor said she wanted to say hi to the patient. The neighbor walked right into the apartment without knocking or letting

the patient's pastor know. Although the neighbor had good intentions, it revealed to me how vulnerable the patient is.

In addition to being at risk for violent crime, the patient is also at risk for unsanitary conditions. The patient states that she has accidents frequently, but she cleans them up herself. She is very concerned that her apartment smells of urine, but I was unable to smell it. Once the patient became very sick, and the pastor's wife came and cleaned her up and cleaned her bathroom. While I was glad her pastor's wife is so devoted, I do not know how long the patient was a mess before the pastor's wife was able to check on her.

When I worked at the help desk at the inpatient facility, I walked families to see their family member who was sick. It was a change to see patients surrounded by family members. Not only does the family support the patient, but family members also support each other. When asked if they would like a volunteer, many of the patients with family support declined a volunteer. A dedicated family member can fulfill the role of a volunteer. I believe they provide an even greater value to the patient because the family member is someone with whom the patient is already comfortable.

After the Christmas season, I volunteered to help take down the decorations at the inpatient facility in Springdale. While I was there, a woman was being wheeled into a room on a stretcher. Her husband was talking to a volunteer and crying. He said he had been taking care of his wife at home but was no longer able to care for her at home because her disease was progressing. I could not help but think that the woman must be scared riding into the facility on a stretcher but also that it would be so much worse without her husband there. Later on, I saw the husband being comforted by an older couple, likely his family or friends. It made me realize that the people supporting the patient also need support themselves.

The Circle of Life facility understands the important role that families play in their loved one's end of life. Because of this, they offer many means of support for the family. There is a comfortable lounge outside the patient rooms where family members can relax. There are always free snacks, and hot meals served every day. Brochures about the dying and grieving process are available in the foyer. Even after the patient dies, there is free grief counseling for a year.

Once I was able to visit the home of a patient who did have family support. When I walked in his home, there was a hospital bed in the living room. I felt that the patient, though dying, was still in the center of family life. He was living alone, He was living alone, but his heart disease progressed, and he was told he had a limited life expectancy. He was able to move in with his daughter and will be able to die at home.

Like the patients with family support at the inpatient facility, this patient did not regularly desire volunteers. Volunteers do come every so often so that his daughter can go to one of her own doctor's appointments. On the weekends, the patient's second daughter stays with him when she is off work. This allows the first daughter respite, and the patient a chance to visit with both his daughters. Because his daughters help him, the patient is still able to attend his church. The patient does not have the money to pay for additional help and does not wish to live in an assisted living facility. Without his daughters, he would not be able to die according to his wishes.

While volunteering, I did not meet any patients with absolutely no support. This is likely because patients without support are more likely to die in a hospital or inpatient facility. Some degree of support is needed for a patient to receive hospice care. Because hospice care is associated with better outcomes at the end of life, family support is very important for patients who are dying. Having support allows patients to die according to their wishes.

I took a tour of the Circle of Life facility in Springdale as a part of my End-of-Life and Palliative Care class. We looked at a sample patient room with a pull-out couch for family members. There were huge sliding glass doors so that the patient's bed could be rolled outside. The patients' briefs were kept in a beautiful chest of drawers. This helped the patients and their families feel more at home and less like they were in an abrasive hospital. The facility was beautiful and seemed to be centered around the whole family.

We also got to listen to the palliative care doctor talk about the medical side of hospice. He talked about emergency kits that are put in the home for if the patient is rapidly declining. The emergency kits contain medications for nausea, seizures, and pain. If a patient is near death and needing an emergency kit, there is almost no way they could give themselves the medications without support. The palliative care doctor also showed us advanced directives that are given to the patient. Typically, a family member or friend who knows the patient well will help them fill out the advanced directive. A social worker could help the patient to fill it out, but I imagine it would be more comfortable for someone close to the patient to help them fill out the advanced directive.

In my Palliative and End-of-Life Care class, my teacher told a story about a patient she had who was dying of breast cancer. The woman's organs had shut down, but she kept hanging on and kept hanging on. Finally, the woman's son whispered something in her ear, and within minutes she died. Did the son tell his mom he loved her one last time? No. He told her that her brother had called and said he was sorry. This was not true, but it allowed the woman to die in peace. This woman's son, unlike anyone else, knew how to let her die peacefully. She needed something that only family could give. The woman lacked support from her brother, and it had

such a great impact on her that it was preventing her from letting go. In this case, a lack of support was making her death longer and more painful than it needed to be.

I have used my service-learning experience in other areas of my life. My grandpa is in his eighties and has multiple sclerosis. He has had multiple sclerosis for over twenty years. He is a quadriplegic and requires total care. Most patients requiring such an advanced level of care would be in a nursing home, but through the dedication of my grandma he still lives at home. She is in her late seventies and still lifts my grandpa to transfer him. He can only help very minimally and weighs around 180 pounds. She cooks for him, helps him eat and drink, helps catheterize him, arranges his medications, and transfers him.

Every year my grandma goes on vacation with her sister to help prevent burnout. While she is gone, my grandpa will stay in a nursing home. While he is well cared for, he is unhappy. He is used to being helped immediately when he needs anything and things being done his way. Without the support of his wife, my grandpa, though not actively dying, would not be able to live according to his wishes. He would also not receive the superior level of care that my grandma is able to provide.

Through this service-learning experience, I have learned much about the dying process. Previously, I had little experience with death because I was not around anyone as they were near death. In the Palliative and End-of-Life Care class, I learned the signs someone is nearing death such as the death rattle, Cheyne-Stokes breathing, and mottled skin on the knees. A person withdraws more and more from their loved ones as they near death. Often families will stay up with their loved one through the night as they are dying.

There are common fears that patients have as they are dying. One is the fear they will die alone. Patients who have good family support do not have to be as afraid of dying alone because a family member will stay with them as they near death. Patients also fear dying in pain. Being a part of hospice greatly reduces a patient's risk of dying in pain. In addition, family members can give the patient small drops of morphine to give immediate relief in emergencies.

Through this service-learning project, I have developed a greater appreciation for the role that family members play when a patient is dying. Family support helps patients both emotionally and physically. As a nurse, I am motivated to work closely with family members for the better care of the patient. If I have a patient without support, I will be more likely to try to find a family member who would support the patient. If no family exists, I could ask a volunteer to spend time with the patient. I am excited to see what else I will learn as I continue volunteering in hospice.

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